

10 Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
 2. Watch out for signs of depression, and don't delay in getting professional help when you need it.
 3. When people offer to help, accept the offer and suggest specific things that they can do.
 4. Educate yourself about your loved one's condition and how to communicate effectively with doctors.
 5. There's a difference between caring and doing. Be open to technologies and ideas that promote your loved one's independence.
 6. Trust your instincts. Most of the time they'll lead you in the right direction.
 7. Caregivers often do a lot of lifting, pushing, and pulling. Be good to your back.
 8. Grieve for your losses, and then allow yourself to dream new dreams.
 9. Seek support from other caregivers. There is great strength in knowing you are not alone.
 10. Stand up for your rights as a caregiver and a citizen.
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Tips for Family Caregivers from Doctors

- Write questions down so you won't forget them
 - Be clear about what you want to say to the doctor. Try not to ramble.
 - If you have lots of things to talk about, make a consultation appointment, so the doctor can allow enough time to meet with you in an unhurried way.
 - Educate yourself about your loved one's disease or disability. With all the information on the Internet it is easier than ever before.
 - Learn the routine at your doctor's office and/or the hospital so you can make the system work for you, not against you.
 - Recognize that not all questions have answers—especially those beginning with "why."
 - Separate your anger and sense of impotence about not being able to help your loved one as much as you would like from your feeling about the doctor. Remember, you are both on the same side.
 - Appreciate what the doctor is doing to help and say thank you from time to time.
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Care Management Techniques You Can Use

Did you ever wish you could just pick up the phone and call someone who would take stock of your situation, help you access the right services, counsel you and your family to help resolve some of your differences, then monitor your progress with an eye toward channeling your energy and abilities as effectively as possible? If your answer is "yes," you're not alone. Having the help of a care coordinator (often called a care manager) could make all of our lives easier and less lonesome, and help us be more capable family caregivers. While most of us may not have access to a care coordinator, we can all learn how to think and act like one, thereby reaping numerous benefits for our loved ones and ourselves.

What Is Care Coordination?

Although every case is different, the care coordination approach usually involves:

- Gathering information from healthcare providers;
- An assessment of your care recipient and the home environment;
- Research into available public and/or private services and resources to meet your loved one's needs; and
- Ongoing communication between all parties to keep information up to date and services appropriate and effective.

Unfortunately, an assessment of your abilities and needs is not necessarily a standard part of the process, but it should be. A complete view of the situation cannot be gained without one. An objective analysis of your health, emotional state, other commitments, etc., are key elements in determining how much you can and cannot do yourself, and what type of outside support is needed to ensure your loved one's health and safety.

Become Your Own Care Coordinator

By learning and applying at least some of the care coordination techniques and ideas that follow, you'll be in a much better position to develop an organized course of action that will, hopefully, make you feel more confident and in control — a goal well worth working toward.

Educate yourself on the nature of the disease or disability with which you're dealing. Reliable information is available from the health agency that deals with your loved one's condition and the National Institutes of Health. When using the Internet, stick with wellknown medical sites. Understanding what is happening to your care recipient will provide you with the core knowledge you need to go forward. It will also make you a better advocate when talking with healthcare professionals.

Write down your observations of the present situation including:

- Your loved one's ability to function independently, both physically and mentally.
- The availability of family and/or friends to form a support network to share the care.
- The physical environment: Is it accessible or can it be adapted at reasonable cost?
- Your other responsibilities — at work, at home, and in the community.
- Your own health and physical abilities.
- Your financial resources, available insurance, and existence of healthcare or end-of-life documents.

This assessment will help you come to a realistic view of the situation. It will let you know the questions to which you need answers. It can be a handy baseline for charting your caregiving journey and reminding you just how much you've learned along the way.

Hold a family conference. At least everyone in the immediate family should be told what's going on. A meeting can set the stage for divvying up responsibilities so that there are fewer misunderstandings down the road when lots of help may be needed. A member of the clergy, a professional care coordinator, or even a trusted friend can serve as an impartial moderator. A family meeting is a good way to let everyone know they can play a role, even if they are a thousand miles away. It can help you, the primary family caregiver, from bearing the brunt of all the work all of the time.

Keep good records of emergency numbers, doctors, daily medications, special diets, back-up people, and other pertinent information relating to your loved one's care. Update as necessary. This record will be invaluable if something happens to you, or if you need to make a trip to the ER. If you can maintain a computer-based record, that will make updating all that much easier and it might even allow you to provide the medical team with direct access to the information.

Join a support group, or find another caregiver with whom to converse. In addition to emotional support, you'll likely pick up practical tips as well. Professionals network with each other all the time to get emotional support and find answers to problems or situations they face. Why shouldn't family caregivers?

Start advance planning for difficult decisions that may lie ahead. It's never too early to discuss wills, advance directives, and powers of attorney, but there comes a time when it is too late. It is also vital that you and your loved one think through what to do if you should be incapacitated, or, worse, die first. It can happen.

Develop a care team to help out during emergencies, or over time if your situation is very difficult. In an ideal world there will be lots of people who want to help. More likely you'll be able to find one or two people to call on in an emergency or to help with small chores. The critical thing is to be willing to tell others what you need and to accept their help.

Establish a family regimen. When things are difficult to begin with, keeping a straightforward daily routine can be a stabilizer, especially for people who find change upsetting and confusing.

Approach some of your hardest caregiving duties like a professional. It's extraordinarily difficult to separate your family role from your caregiving role, to lock your emotions up in a box while you focus on practical chores and decisions. But it is not impossible to gain some distance some of the time. It requires an almost single-minded approach to getting the job at hand done as efficiently and effectively as possible. It takes practice, but is definitely worth the effort.

Additional Resources

It's always wise to find out what your county and state have to offer in the way of services, even if you think you won't qualify for them. Check the blue pages of your phone book for the numbers, or go on line. Counties and states all have web sites. Type the name of your state or county and state into any major search engine i.e. Iowa, or Montgomery County, PA. Navigate from there to locate the Department of Health and Human Services and the specific office most relevant to your needs such office on disabilities, elder affairs, or material and child health.

Other good sources of information include your local hospital or clinic (social work department), area adult day centers, social service and faith-based agencies, and/or the local chapter of the health agency that focuses on your loved one's condition. It is by no means certain that any of these will offer caregiver support services, but they are good places to check, and they are good sources for information about services to directly support your loved one.

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The National Family Caregivers Association (NFCA) is a grassroots organization created to educate, support, empower and advocate for the millions of Americans who care for chronically ill, aged, or disabled loved ones. NFCA is the only constituency organization that reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers. NFCA serves as a public voice for family caregivers to the press, to Congress and the general public. NFCA offers publications, information, referral services, caregiver support, and advocacy.